

Consumer and Citizen Participation in Health Care: Where are the Principles for Ethical Conduct?

ANNE JOHNSON, SHARON LAWN AND JANET STRUBER

Many health services strive to actively involve consumers and citizens in improving service provision and the safety and quality of health care. However, some health professionals and consumer and citizen participants have raised concerns about ethical issues that have emerged as a consequence of how some of these participation processes are implemented. Issues raised by both health professionals and consumer and citizen participants relate primarily to tokenism and social control practices. It is of paramount importance that the health sector develops ethical principles to underpin ethical conduct for consumer and citizen participation, and define accountability mechanisms to support ethical conduct. This not only protects consumer and citizen participants, but also health professionals.

Increasing Recognition of the Importance of Consumer and Citizen Participation

Effective consumer and citizen participation is seen as an integral component of ensuring improvements in service delivery and the safety and quality of health care, and for reducing the risk of adverse events (Australian Council for Safety and Quality in Health Care 2003; The Australian Council on Healthcare Standards 2002). In recent years increased recognition and acceptance of the value of involving consumers and citizens in decision making to help shape health systems has been evident. Such participation helps health services to become more inclusive, accountable, and responsive to health consumers and broader community needs, whether at a policy level, health service level or individual care level (Victorian Government Department of Human Services 2005; Government of South Australia 2003; Johnson 2001; Commonwealth of Australia 1993).

Emerging Ethical Concerns

Health services use a diverse range of methods of participation including formal committee and working group structures, and more ad hoc consultation and feedback mechanisms. Inherent in most participation methods are the dilemmas of whether consumers and citizens are active or passive participants; and the potential power imbalance between health professionals who typically control the agenda and consumers and citizens who can struggle to have their voices heard.

Several commentators have identified that a pretext of consumer and citizen participation can be used when the real intention is to inform consumers and citizens of decisions already made by health services to meet government directives and/or to maintain managerial legitimacy (Harrison & Mort 1998). It has also been determined that consumer and citizen participation has seldom influenced or modified management decisions (Draper & Hill 1995; Summers & McKeown 1996; Harrison

et al. 2002). Buetow (2003) concluded that over-preparation (where the consulting party has, or appears to have, made a final decision independent of the consultation) and under-preparation (the result of poorly developed proposals and not giving citizens enough information for effective involvement) were two conditions that can compromise the ethics of citizen participation. Kroshel (2005) identified similar ethical issues as barriers to effective consumer participation that still persist within the health sector and are issues that consumers have had to battle with for many years. These research findings have identified some of the ethical dilemmas which result in tokenistic or manipulative processes for achieving and demonstrating consumer and citizen participation by health services.

One of the first researchers to identify this problem was Arnstein (1969). Arnstein's developed a Ladder of Participation with eight rungs. "Manipulation" is identified as the first rung of the ladder and described as non-participation, the third to fifth rungs of the ladder are described as "degrees of tokenism". Arnstein (1969) states that with "manipulation" the real objective is not to enable people to participate, but to enable power holders to "educate" the participants to the "professional's" view of the issue and solutions. Others refer to manipulation as being a form of "social control", where participatory processes are used to regulate consumer and citizen behaviour for the purpose of ensuring compliance and conformity.

Tokenism occurs when the power-holders seek input from consumers and citizens but the method of participation means that consumers and citizens lack the power to ensure that their views are heeded by the power holders. With tokenism there is no follow through and no assurance of changing the status quo (Arnstein 1969). Whether this outcome of participation is deliberate, or has occurred out of ignorance, does not change the fact that these are unethical practices. In addition, such practices may create an unrealistic expectation of the service. This in turn may lead to greater mistrust or dissatisfaction with the service by consumers.



Ethical Conduct of Health Research

Traditionally the concept of "ethical conduct" has only applied to research conducted by health professionals, with the aim of protecting the welfare and rights of research participants. The principles of ethical conduct for research include: integrity, respect for persons, beneficence and justice; research merit and safety; and ethical review and conduct of research (National Health and Medical Research Council 1999). More recently guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research have been developed and include the values of spirit and integrity, reciprocity, respect, equality, survival and protection, and responsibility (National Health and Medical Research Council 2003). The National Health and Medical Research Council (2002, p. v) has adopted a Statement on Consumer and Community Participation in Health and Medical Research which recommends that:

- consumers be given the opportunity to participate in decisions about what types of research should have priority;
- consumers who take part in research be told about the outcomes of that research; and
- researchers involve the community in the research process by disseminating information about the role, benefits and results of research, consequences of new areas of research and ethical issues.

Stringent systems and processes are set up within the health sector to ensure ethical principles are applied to most research. Some health services have linked aspects of consumer and citizen participation management to the research ethics processes in their organisations to ensure ethical management (Women's and Children's Hospital 2006). While this practice addresses issues related to the ethical management of consumer participation strategies that are congruent with the research ethical principles, it does not address broader ethical issues of participatory practices which should ideally be in place to reduce the occurrence of tokenism and manipulation (or social control).

Conclusion

There is an urgent need for health consumer organisations, health services, health departments, and leading quality health organisations such as the Australian Commission on Safety and Quality in Healthcare, Australian Patient Safety Foundation, and The Australian Council of Health Care Standards to work together to develop guiding principles for ethical conduct for consumer and citizen participation in health services. There is a further need to develop recommendations and clear processes for implementation based on these principles, to ensure health services are accountable for implementing these ethical principles so that they become an integrated and sustainable part of how services work with consumers and communities.

Anne Johnson is Associate Professor in Public Health, Department of Public Health, Flinders University, South Australia.

Sharon Lawn is Project Officer, Consumer and Carer Participation, Southern Mental Health, Adelaide.

Janet Struber is Manager, Consumer Complaints and District Liaison, Queensland Health, Cairns.

Acknowledgements

The authors would like to acknowledge the many health professionals, consumers and community members who have enthusiastically contributed their ideas about this important issue at the short courses held by the Department of Public Health, Flinders University.

References

- Arnstein, S. 1969, 'A ladder of citizen participation', *American Institute of Planners Journal*, No. 5, pp. 216-224.
- Australian Council for Safety and Quality in Health Care 2003, *National Action Plan Update*. Retrieved 22 March 2007 from www.safetyandquality.org/articles/Publications/natactnplanjul03.pdf.
- Buetow, S. 2003, 'The ethics of public consultation in health care: An orthodox Jewish perspective', *Health Care Analysis*, Vol. 11, No. 2, pp. 151-160.
- Commonwealth of Australia 1993, *Healthy Participation: Achieving Greater Public Participation and Accountability in the Australian Health Care System, National Healthy Strategy Background Paper No. 12*, Commonwealth of Australia, Canberra.
- Draper, M. & Hill, S. 1995, *The Role of Patient Satisfaction Surveys in a National Approach to Hospital Quality Management*, Commonwealth Department of Health and Family Services, Canberra.
- Government of South Australia 2003, *First Steps Forward South Australian Health Reform*. Retrieved 22 March 2007 from www.sahealthreform.sa.gov.au/
- Harrison, S. & Mort, M. 1998, 'Which champions which people—public and user involvement in health care a technology of legitimation', *Social Policy and Administration*, No. 32, pp. 60-70.
- Harrison, S., Dowswell, G. & Milewa, T. 2002, 'Guest editorial: public and user involvement in the UK national health services', *Health and Social Care in the Community*, No.10, pp. 63-66.
- Johnson, A. 2001, 'An outline of consumer participation in health', *Collegian, Journal of Royal College of Nursing Australia*, Vol. 8, No. 2, pp. 25-27.
- Kroschel, J. 2005, 'Consumer participation in health: where are we after 10 years?', *Health Issues*, Issue 85, pp. 9-11.
- National Health and Medical Research Council 1999, *National Statement on Ethical Conduct in Research Involving Humans*, Commonwealth of Australia, Canberra. Retrieved 22 March 2007 from www.nhmrc.gov.au/publications/synopses/e35syn.htm
- National Health and Medical Research Council 2002, *Statement on Consumer and Community Participation in Health and Medical Research*, Commonwealth of Australia, Canberra.
- National Health and Medical Research Council 2003, *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*, Commonwealth of Australia, Canberra.
- Summers, A. & McKeown, K. 1996, 'Local voices: evolving a realistic strategy on public consultation', *Public Health*, No. 110, pp. 145-150.
- The Australian Council on Healthcare Standards 2002, *ACHS EquiP Standards*, 3rd edn. Retrieved 22 March 2007 from www.easternhealth.org.au/boxhill/standards-june2002.pdf
- Victorian Government Department of Human Services 2005, *Participation in your Health Service System: Victorian Consumers, Carers, and the Community Working Together with their Health Service and the Department of Human Services*, Metropolitan Health and Aged Care Services Division, State of Victoria, Department of Human Services.
- Women's and Children's Hospital 2006, *Bringing in the Voice of the Consumers*, 3rd edn, Children, Youth and Women's Health Service, Adelaide, pp. 51-52.